Caring for a child with a congenital limb difference

What is a congenital limb difference and what causes it?
Congenital limb difference (also known as congenital limb deficiency) is when a baby is born missing all or part of the upper and/or lower limbs. It is sometimes due to amniotic band syndrome – where the amniotic band, a fibrous string-like structure, restricts blood flow and affects the development of a limb. Sometimes there is a genetic link or an association with another illness. The cause of congenital limb difference is often unknown.

Can congenital limb difference be prevented?
There is no known way to prevent a congenital limb difference. It is generally an isolated health condition and, with the exception of a few rare syndromes, is not linked to other conditions.

What happens next?
After your baby is born the hospital can arrange a time for you to meet with a team of specialists. They will be able to answer your questions and advise you on any potential reconstructive surgery. Some children will need surgery and other children will not. Surgery is sometimes necessary for children with leg differences so that an artificial limb (prosthesis) can be fitted when your child gets older. It is less common for surgery to be required for children with arm differences. Each child is different and different surgical options will be offered on an individual basis.

If surgery is recommended it is important to speak with the medical team involved and ensure you understand why it is being recommended and what the expected outcomes are. If you need to make a decision for your child, take the time you need, seek information and be comfortable with your choice.

An allied health team will also be available to help you and answer any questions. Members of this team may include:

- **An occupational therapist** – who will work to help your child become as independent as possible with everyday activities. They can help with assistive devices and ‘skills’ based training for upper limb differences.

- **A physiotherapist** – who will generally focus on gross motor skills such as running, skipping, jumping and hopping. They assess walking and might guide you through exercises to optimise your child’s movement and mobility.

- **A social worker** – who will work with you and your family to provide you with access to support and confidential counselling.

- **A prosthetist** – who will assess and manufacture prosthetic limbs for your child. Prosthetists can provide artificial arms and legs to help with function and also for cosmetic reasons. Prosthetic limbs need lots of adjusting as your child is growing.

- **A maternal and child health nurse** – who will provide you with information, guidance and support regarding parenting as well as your child’s health and development.

Looking after yourself
Some parents learn of their child’s limb difference before they are born, while others find out when they first meet their baby. In both cases it is likely this news will be distressing. Parents often experience conflicting feelings such as the joy and excitement of expecting or finally meeting their new baby, along with feelings of uncertainty about the future and the challenges it may bring. It is normal to experience shock, disbelief, anger, blame and sadness as well as feelings of grief and loss. Our information sheet ‘dealing with grief and loss’ provides some strategies to help parents of children with a congenital limb difference understand and deal with these emotions.
**You are not alone**

Allow yourself the time and space to process this news both mentally and emotionally. Be patient with yourself and be assured that your feelings of uncertainty will subside with time. It is important to remember that you are not alone. Speaking and meeting with other parents of children who have a limb difference can be of great value and provide an insight that other parents or friends cannot. Limbs 4 Life can put you in touch with a volunteer who is a parent or carer of a child with a limb difference. Remember that your child will have the same needs and desires as any other child and nothing should stand in the way of them leading an active, happy and fulfilling life.

**Other resources you may find helpful:**

**Children’s books** ([www.amputee-coalition.org/fact_sheets/help_child_understand.pdf](http://www.amputee-coalition.org/fact_sheets/help_child_understand.pdf))

Children’s books featuring characters with a limb difference can help a child with limb difference have greater self-esteem and identify with characters that “look like me” or are “different like me.” Children can find encouragement to talk about their limb difference openly and answer questions from friends.

**Genetic Support Network Victoria (GSNV)** ([8341 6315; www.gsnv.org.au](http://www.gsnv.org.au))

A network for families affected by a genetic condition that provides information, support and advocacy.

**Maternal and Child Health Line** ([13 22 29](http://www.mothercare.org.au))

A Victorian Government service staffed by maternal and child health nurses who provide information, support and advice regarding child health, maternal and family health and parenting issues.


A statewide telephone counselling service to parents and carers of children aged from birth to eighteen years.

**Post and Antenatal Depression Association Inc (PANDA)** ([1300 726 306; www.panda.org.au](http://www.panda.org.au))

An organisation offering a helpline, education, training and a home visiting service for parents affected by post and antenatal depression.

**The Aussie Hands Foundation Inc** ([9671 4242; http://www.aussiehands.org](http://www.aussiehands.org))

An organisation supporting children and adults who have been born with a hand difference and to those who have an acquired hand injury.

**The UK Limb Loss and Information Centre** ([www.limblossinformationcentre.com](http://www.limblossinformationcentre.com))

An online resource to guide individuals with congenital or acquired limb loss and their friends, family and carers through the emotional, physical and psychological process of coming to terms with limb loss.

For further information contact Limbs 4 Life

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